

Delaware Developmental Disabilities Council (DDC)
Adult Issues Committee
Minutes of Meeting
Friday, May 19, 2017 * 10:00 AM to 12:00 PM
Appoquinimink State Service Center, Large Conference Room
Middletown, DE

Members present: Terri Hancharick, Committee Chair, Parent Advocate; Alvin Emory, Self-Advocate; Barbara Monaghan, Self-Advocate; Bill Monaghan, Self-Advocate; Gary Mears, Parent Advocate

Members absent: Karen Gallagher, Self-Advocate, Committee Vice-Chair; Vivian Turner, CERTS; Laura Strmel, St. John's Community Services (SJCS); HarrietAnn Litwin, Division of Vocational Rehabilitation (DVR); Carol Barnett, Division of Services for Aging Adults and Physical Disabilities (DSAAPD); Derrick George, Advocate

Guests Present: Diann Jones, Advocate

Staff present: Kristin Harvey, Social Services Administrator, Delaware Developmental Disabilities Council (DDC)

I. Call to Order: The meeting was called to order at 10:05 AM.

II. Approval of Minutes: The committee voted to approve the April, 2017 minutes as written.

III. Approval of Agenda: The committee voted to approve the agenda with two requested additions. The addition of nominating new officers and exploring if any changes were needed in the State Plan were placed under "new business".

IV. -Chair's Report: Terri asked if it were possible to add an employment goal to the state plan. Following discussion about the Council's required timelines for State Plan Updates, it was decided to postpone the discussion about adding a goal until next summer.

V. - Staff Report: Kristin reminded the committee that Junior Partners in Policymaking will take place from June 18-23 at Delaware State University. All members of the Council are welcome to attend and see what the program is about.

VI. Current Business

A. Discussion with Diann Jones RE: becoming your own best health advocate:

Diann thanked the committee for their time, and for allowing her to attend the meeting. She wanted to share her thoughts about how individuals can become their own best health advocate. Diann stated that individuals who are dealing with illness or disability, particularly for someone who acquires these things at a later age, do not have all the tools they need to help them organize and plan. Some issues that may be encountered include:

- Life is completely different than it was before
- Resources for someone who acquires a disability at a later age are difficult to locate and coordinate
- Forms and paperwork may become more confusing or difficult to complete

- Deductibles and payments require future budget planning, but there is little assistance to help individuals with financial planning
- Multiple doctor referrals are confusing and difficult to keep track of
- Patients need help planning ahead to ensure that they are treated holistically and with respect to their wishes

The committee agreed that the above-mentioned things are concerning. The committee stated that they believe there may be room in the current state plan under the self-advocacy goal to create some sort of training or project regarding personal health care advocacy. The goal would be for individuals who are experiencing disability or illness to have access to a person-centered care plan binder or similar organizational tool. Depending on how each individual person learns and keeps track of things, it may be necessary for some to have access to a recorder, a buddy, an app or a website to help them advocate and stay organized. The committee discussed the varying forms of the Patient Bill of Rights, which can differ between health care organizations. The committee said that they would like to invite Laura Waterland of the Delaware Disabilities Law Program to attend a future meeting and discuss the various forms of post-release Patient Bill of Rights.

B. RFP focused on employment?

This was discussed during the Chair's report. Further discussion will take place and an objective will be considered for next year's state plan update.

C. June and July meetings:-

The committee voted to reschedule their June meeting to June 30th, due to DDC staff availability. The July meeting will remain on July 21.

VII. New Business:

1. The committee voted to nominate Terri Hancharick to serve as Committee Chair again in 2018, and to also nominate Karen Gallagher to continue her work as Committee Vice-Chair in 2018.
2. The committee voted to make no changes to the state plan at this time.

There being no other new business, the meeting was adjourned at 12:05 PM.